

10 Points for Change

What changes do autistic people and their supporters most want in their lives?

Report by Rosie Holt, Siti Ikhsan, and Scarlett Li-Williams

This summary is based on the paper **‘Priorities for change for autistic people across Europe’** currently under review in Molecular Autism. Ikhsan, S., Holt, R., Ruigrok, A., Man, J., Parsons, T., Gibbs, K., Bullock, E., Baranger, A., Allison, C., Doherty, M., Ghosh, A., Tercon, J., Van den Bosch, K., Baron-Cohen, S.

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Autistic People's Top 10 Areas for Change

Autistic people with a formal diagnosis



Education



Public awareness and understanding of autism



Employment



Government funding for autism-specific services



Discrimination



Mental healthcare



Bullying/abuse



Social inclusion



Diagnostic services



Financial hardship



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Parents' and Carers' Top 10 Areas for Change

Includes parents who have an autism diagnosis themselves



Education



Government funding for autism-specific services



Public awareness and understanding of autism



Employment



Social inclusion



Support with daily living



Diagnostic services



Early intervention



Mental healthcare



Post diagnostic support

This research was completed by the University of Cambridge AIMS-2-TRIALS team at the Autism Research Centre in collaboration with A-Reps

Illustrations by Scarlett Li-Williams

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Background

Despite the rise in autism prevalence, quality of life for autistic people in Europe still needs to be improved.

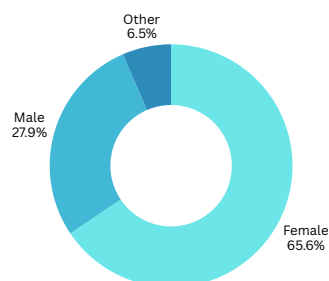
We conducted the '10 Points for Change' survey to identify the 10 most important areas where autistic people and their supporters believe change is needed.

The survey was developed in collaboration with community members. Nineteen areas for change were selected based on focus groups and existing literature in this field. Participants ranked these 19 areas in order of priority, indicating where change is most needed for autistic people, and shared their experiences and suggestions for improvement.

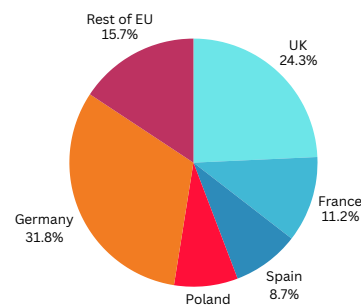
About the Data Collected

- The survey was open from November 2020 to February 2024, and was available in English, Czech, French, German, Italian, Slovenian, Spanish and Polish.
- Participants were EU or UK residents aged 16 and above.
- 1,709 people completed the survey.
- 59% of our sample identified as autistic while 41% were non-autistic. 36% were parents/carers of autistic people. Out of this group, 19% were autistic while 81% were non-autistic. 17% were members of autism organisations. Out of this group, 27% were autistic while 73% were non-autistic.
- The average age of participants was 42 with ages ranging from 16-97 years of age.

Gender



Country



Key Findings Overview

- Overall, there was broad agreement across participant groups about which areas were most important for change. All groups agreed **education, public awareness and understanding of autism, employment, government funding for autism-specific services, mental healthcare, social inclusion and diagnostic services** were important areas for change for autistic people.
- Parents and members of autism-related organisations ranked **support for daily living, early intervention and post-diagnostic** support within the top 10 priorities, which differed from the top 10 priorities identified by the autistic people group.
- Members from autism organisations had very similar priority ranking to parents.
- Autistic people prioritised **discrimination and bullying/abuse** as areas they thought most needed to change compared to the other groups.
- Autistic people without a formal diagnosis prioritised **diagnostic services** more highly, but otherwise their priority rankings were similar to formally diagnosed autistic people.
- Across countries, the community priorities were similar.

Please note this work is currently unpublished – details of publication will be shared subsequently.